CONGRÈS INTERNATIONAL DE SOINS PALLIATIFS McGILL
McGILL INTERNATIONAL PALLIATIVE CARE CONGRESS

# Conversation with Ira Byock:
## Intentional Branding of Palliative Care

*In May 2022, Devon Phillips, Program Advisor for Palliative Care McGill, sat down with Ira Byock, MD, FAAHPM, for the following interview.*

**Devon Phillips (DP): At the International Congress on Palliative Care [https://www.mipcc.ca/agenda] October 18-21, 2022, you will be speaking in a plenary session called "The Public Face of Palliative Care: The Brand We Want to be Known By". What is our "brand" currently?**

**Ira Byock (IB):** We have a brand by default, but there is a lot of discrepancy about what people think that brand is and what it means. Part of the origin story of palliative care in North America is that Bal Mount realized that the word "hospice" was not going to be well accepted in French-speaking Quebec and chose the phrase "palliative care" and that has served us well. But now "supportive care" is being used increasingly as a euphemism for palliative care because clinicians in our field are often told that the term "palliative care" scares their patients: "Please don't mention that you are from palliative care when you are in the room. Could you please call yourself supportive care or comfort care or something else?"

On the other hand, people from the Centre to Advance Palliative Care (CAPC) in New York City have done market research that purports to show that we should never use the term "hospice" when we are talking to patients. I am in respectful disagreement.

They have also been encouraging clinicians not to use the words "death", "dying", or "hospice care" but rather to emphasize that we are an extra layer of professional support for people and their families going through serious illness.

I completely understand the intention of making sure that access to our services is available to all who need it and that they are not put off by thinking that we are only about death and dying, but it seems that we are acting from fear rather than acting from a sense of confidence and frankly, from love.

**DP: How do we infuse the concept of acting from love into palliative care when there is so much fear of palliative care?**

**IB:** We start by being called by our authentic name. We came together as the field of hospice and palliative care. We have to own it. We are about living, not just about dying, and dying is a part of living. Many of us act as if we are only about dying. Because of short staffing and the pressures of time and budgets and all that, we may only be able to accept people into our palliative care programs who are at the far edge of life and at significant risk of dying. We may be unable to accept all who have a serious illness, including those who are engaged in curative treatments or treatments to extend their life significantly and fight the disease.

I spent a decade at Dartmouth medical school and Dartmouth–Hitchcock Medical Center. One day I was walking down the backstairs with an oncologist colleague who paused in the stairway, and said, "When you came here three years ago, they made a big to-do about us expanding our palliative care service and I thought, 'why do we need another service? We do this stuff all the time and this is so unnecessary.' But I have to tell that at this point, I cannot remember how we used to take care of these people without you and your team." I replied, "Wow thanks so much for saying that. I can't tell how gratifying it is to work so closely with you." And we went down a few steps and then he turned around and he said, "Do you have to use the name 'palliative care' because it scares the daylights out of people." And I said, "Well that's really ironic. You want to know a word that scares the hell out of people? It's cancer. I'll change the words 'palliative care' for our program when you change 'cancer centre' to 'little funny bump centre' because the word cancer scares the shit out of people!"

What we need to do is change the *meaning* of palliative care. It should not mean you are dying. It should mean you are pretty sick and deserve the extra layer of support that this specialized team can offer you and your family.

**DP: So palliative care practitioners need to intentionally change how they define and communicate what they do?**

**IB:** In our medical centre, we intentionally rebranded palliative care. The term began to connote deserving extra layers of attention to people's decision support, their physical comfort, emotional comfort, their family's support, attention to communication, continuity of care, collaboration with the various teams treating their organ systems and their disease – all of that. We gave our service a new very intentional meaning, not allowing others to brand us by what they thought palliative care meant.

The last book I published was called "The Best Care Possible" [link: https://irabyock.org/books/the-best-care-possible/] because I fully believe that's the authentic brand of palliative care. It's not a one-size-fits-all model. Unless I meet you as a person and find out about your personal values and preferences within the context of who you are as a whole person – including your ethnicity, your spiritual orientation, your family – I can't give you the best care possible. Because I am trying to attend to your wellbeing, not just your medical problems. I still think the "best care possible" is a good phrase for our authentic brand. We meet every person as a unique, whole person and we tailor the best of medical science and technology and disease treatments to their personal priorities. Given two people with the same age, gender, medical history, the best care for one might be entirely the wrong care for the other. Optimal care has to be highly personalized.

**DP: What can the palliative care community do to get this message and brand of "best care possible" out there**?

**IB:** Right now there is no consensus about what the term "palliative care" means. So first we need to coalesce around a commitment to bring new and life-affirming meaning to the term "palliative care" and in the US, to include hospice care, without allowing others to brand us. Our messaging must consistently come from a place of love, acceptance and welcoming of *all of life*, and not from a sense of fear, hiding or avoidance.

Part of my own contribution to the conceptual frameworks of our field has been to explore the phenomenon of human wellbeing through the very end of life, because medicine in the western world is tightly bound to and constrained by problems and their solutions. We need to embrace the fullness of human life including the stages of life in which illness and caregiving and dying are difficult but normal parts of full and even healthy living. In that more anthropologically rooted view of the fullness of human life, what we do in palliative care is to provide the best care possible for you through the very end of your life. To date, because we have not owned that as our brand, we are known by other people's assumptions and their projected expectations of us.

**DP: You have been an important figure in the International Congress on Palliative Care congress for many years. In 2022 you will be a plenary speaker. Does the congress support you in building the brand of palliative care you describe?**

**IB:** Yes. The congress is a truly international event that brings together thought leaders from around the globe to learn together, to share state-of-the-art knowledge and to wrestle together with the cross-cutting challenges that many of us are having in our respective countries and communities. It has been for me the most important clinical home that I have had in my education as a hospice and palliative care provider. I find that the International Congress in Montreal has been energizing and enervating and source of enormous stimulation, fellowship and camaraderie over the many decades.

**DP: The planning for the International Congress on Palliative Care is coming together beautifully for 2022 and we look forward to your plenary. Do you have any last message or thoughts to share with our readers?**

**IB:** I want to emphasize that every patient is a whole person with the capacity to suffer but also the capacity for well-being. This is not pop psychology; this is core anthropology. It is our job not only alleviate suffering, but also to hold open the potential for people to grow individually and together through the end of life.

If we own that and assert that that is what we are about to our colleagues, we will begin to call ourselves by our authentic name. That's the start of people seeing us as we would like to be seen and acting in accordance with who we are.

If we are to give the best care possible, we need to bring our whole selves to care for the wholeness of patients' personhood. Instead of feeling the moral distress that we are currently feeling as clinicians, we can begin to feel gratified by the deep connections we have with the whole persons we serve. This brings us back to where we all started. In the book "The Hospice Movement: A Better Way of Caring For the Dying" [https://www.goodreads.com/en/book/show/514993.Hospice_Movement], Sandol Stoddart talked about hospices as places where people are cherished and refreshed, a place of welcome, and a loving environment. She said hospice is an intimate transaction between human beings in community. It is time that we reaffirm that that's what we are about, that medicine and the science and technology are the tools that we use, but what we are about is an intimate transaction between whole persons living in communities in service to one another.

*This interview has been edited for length and clarity*

*Dr Byock will be a plenary speaker, along with Drs Hsien Seow and Samantha Winemaker who host the Waiting Room Revolution [*https://www.mipcc.ca/agenda/*] and Dr. Kwadwo Kyeremanteng, who hosts Solving Healthcare [*https://drkwadwo.ca/*], on the topic "The Public Face of Palliative Care: The Brand We Want to be Known By", at the International Congress of Palliative Care [*https://web.cvent.com/event/ff07cfad-8649-4987-a263-6da4bed04e30/summary*] to be held in Montreal, October 18-21, 2022.*